

# Palliative Care and Quality of Life Interdisciplinary Advisory Council

April 25, 2014 Meeting Minutes

## Members Present:

**Jean Anderson, R.N.**, CEO, Visiting Nurses Service of Newport and Bristol Counties; **Maria Barros, R.N.**, Director of Clinical Services, Nursing Placement, Inc.; **Rev. Marie Carpenter**, Director of Eldercare Ministries, American Baptist Churches of Rhode Island; **Dr. Linda DelVecchio-Gilbert**, Associate Professor, New England Institute of Technology, Nursing Department; **Linda M. Dziobek, R.N.**, Chair, Partnership to Reduce Cancer in Rhode Island; **Chair of the Advisory Council, Dr. Edward V. Martin, M.D., MPH**, Medical Director, Home and Hospice Care of Rhode Island; **Nancy Roberts, R.N.**, President and CEO, VNA of Care New England Health System; **Dr. Angela Taber, M.D.**, Palliative Medicine Physician, Miriam Hospital and Rhode Island Hospital.

## Members Not Present/ Excused:

**Dr. Joan M. Teno**, Professor of Health Systems, Policy, and Practice, Brown University School of Public Health (excused)

## Staffing the Advisory Council:

**C. Kelly Smith, MSW**, Comprehensive Cancer Control Program, Rhode Island Department of Health; **Dr. Manuela Raposo, M.D.**, Comprehensive Cancer Control Program, Rhode Island Department of Health

## Members of the Public Present:

**Vivian Spencer**, representing United States Senator Sheldon Whitehouse; **Dr. Seth Bock**, Greenleaf Medical Marijuana Dispensary; **Todd W. Ellison, MSW, LICSW**, American Cancer Society Cancer Action Network; **Gina Marie Rochon**, Hospital Association of Rhode Island

## Minutes:

### 1. Introductions, Roll Call and Establishment of a Quorum (Chair)

Dr. Martin welcomed and thanked the Council Members and Members of the Public. He then called roll (results above). A quorum of the Council was determined to be present.

### 2. MOLST (Medical Orders for Life-Sustaining Treatment) Recommendations for Director of HEALTH: Discussion

The Council discussed MOLST (Medical Orders for Life-Sustaining Treatment). Highlights of the discussion:

- Attach the MOLST to the Continuity of Care form and add check-offs to the Continuity of Care form (version 5.0, available on HEALTH's website) as follows:
  - Page 2, under "Does the Patient have an Advanced Directive?" Options should be: No, Yes
  - Then, under that: Full, DNR, CMO, MOLST (check off)
  - Also, Page 5, under "Does the patient have an Advanced Directive?" Options should be: No, Yes
  - Then, under that: Full DNR, Partial DNR, MOLST (check off)

- Amend the HEALTH website to include the following information about Palliative Care:
  - The PowerPoint presentation from Palliative Care grand Rounds (2013)
  - Links to the MOLST and Continuity of Care forms
  - The FAQ sheet developed by Maureen Glynn to explain the benefits of the bill that passed
  - A recorded YouTube fireside chat by Dr. Fine on palliative care and MOLST—specifically, the talk that he gave at the MOLST Train the Trainer event
- Ideally, we should develop a universal method of indicating that a patient has a MOLST, e.g.:
  - Most recent order should be flagged and incorporated into a patient’s electronic medical record
  - Suggestion: something to post on a patient’s refrigerator if at home indicating there is a MOLST (EMTs routinely check refrigerators now)
  - Bracelet? The Advisory council discussed this and decided that this would not work.
  - After prolonged discussion, the Advisory Council decided to remove this item from the list of requests for HEALTH, as long as efforts are made to incorporate MOLST into CurrentCare
- The Advisory Council discussed translating the MOLST form and its instructions into languages other than English. Many first responders and providers are not bilingual. The Council decided that the MOLST form itself should remain in English (and physicians should fill it out in English), but that the accompanying instruction sheet should be translated ASAP into Spanish, Portuguese, and any other languages deemed necessary.
- Adapt Dr. McDonald’s segment of the Grand Rounds training into a webinar for CME credits
- Recommend that Dr. Fine request that the state’s licensure boards incorporate MOLST training into the individual and facility licensure processes, and inspections/ reviews. Survey the licensed facilities re: their policies, practices, and familiarity with MOLST forms. Evaluation will be needed—are agencies/ hospitals completing the MOLST forms, frequency of updates, quantity completed or updated each month, etc.
- Members asked whether we can learn any lessons from the experiences of other states.

### **3. Palliative Care Definitions**

The Council began to discuss definitions of palliative care.

- Palliative Care is often interchanged with advanced illness terminology (Linda DelVecchio).
- Mount Sinai Cancer Center oncologists asked that palliative care be called the “Supportive Oncology Program (Dr. Martin).
- Members discussed the public’s confusion of palliative care with hospice care
- Palliative care is more concerned with symptom management (Linda Dziobek).
- Rhode Island has late entry into hospice care, so palliative care is often confused with hospice and end of life care here, or considered part of those processes only.
- People are often uncomfortable talking about death and the end of life. The committee should review the findings of Healthcentric Advisors, which is doing a palliative care implementation study with Rhode Island nursing homes (Marie Carpenter, who is on Healthcentric’s project steering committee)
- The Council should become more familiar with the Conversation Project.

**4. Topic for Consideration at Next Meeting:**

- Determine what information to provide to the public and providers as to what palliative care is, and what it is not.
- Begin to work on a glossary of terms for palliative care.

**5. Future Meetings**

Next meeting dates are as follows:

- June 27
- August 22 (Note: must be rescheduled at June 27 meeting)
- October 24
- December meeting is TBD (Note: must be scheduled at June 27 meeting)

**6. Adjournment**

The meeting was adjourned at 4:40pm.

(Minutes reported by C. Kelly Smith, MSW)